



2014 Annual Report



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A Year in Review

2014 was an incredible year for the PKD Foundation of Canada, and one that saw our organization and the PKD community celebrating many inaugural achievements. We are thrilled with how much has been accomplished in just 12 months, and look forward to highlighting these benchmarks with you in this year's Annual Report.

In April, the PKD Foundation of Canada launched our newest chapter in Montreal. Being the first group in the Province of Quebec, we were able to start providing support and literature to the many Francophone members of the PKD community situated in the Greater Montreal Area. The Montreal Chapter hit the ground running, hosting a highly successful first fundraiser in August, while working diligently to promote the PKD Foundation of Canada and their first educational support group meeting.

For the very first time, Health Canada recognized September 4th as National PKD Awareness Day. This special day was devoted to raising awareness of polycystic kidney disease and the critical need for treatments and a cure. We focused extensively on social media and encouraged those in the PKD community to join in the conversation on our Facebook and Twitter pages, where we provided them with profile pictures and graphics to share, tools to promote their personal PKD stories and more! In addition to the success found on social media, we also benefitted from visibility online, on-air and in published print coverage by way of the Metro Ottawa (Ottawa, ON), The Review (Vankleek Hill, ON), St. John's Telegram (St. John's NL), and 580 Newstalk (Ottawa, ON).

In November, the PKD Foundation of Canada hosted the country's first National symposium dedicated to PKD. It was a day filled with valuable information and subject matter relevant to those afflicted by PKD, and included over 100 participants from the PKD medical community and various renal healthcare centres, as well as PKD patients, their families and loved ones. Throughout the day, we heard from top Canadian and International Key Opinion Leaders in the field; learning about important ways to manage various aspects of one's PKD diagnosis.

A Year in Review (cont.)

Over the course of 2014, we also facilitated an autosomal dominant polycystic kidney disease (ADPKD) online survey, to gain invaluable insight into how ADPKD affects your life – emotionally, socially and physically. Thanks to the impressive number of responses received from Canadian ADPKD patients, the data collected from this survey will help us to better serve the PKD community through our various front-line initiatives.

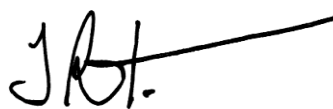
As a small charitable organization, we are so appreciative of our volunteer leadership, donors and supporters in the PKD community across Canada. Without you, we would not be able to achieve the level of success we have in strengthening our various programs and events over the course of 2014. We express our deepest gratitude for your tireless efforts in promoting vital PKD awareness and your generous support through our annual fundraising campaigns. With us being closer than ever to the approval of treatment options for PKD patients here in Canada, it's important to recognize that we have a lot of work ahead of us to ensure those afflicted with PKD no longer suffer the full effects of this disease. We hope you will continue to stand along side us in the fight to end PKD!

From all of us here at the PKD Foundation of Canada, we thank you for what you do to serve the PKD community. Your continued support of our organization will further strengthen our impact in the lives of 66,000 Canadians and 12.5 million people globally living with this disease, and help us to put a face and voice to polycystic kidney disease.

Respectfully yours,



Michael Kenigsberg
Chair, Board of Directors



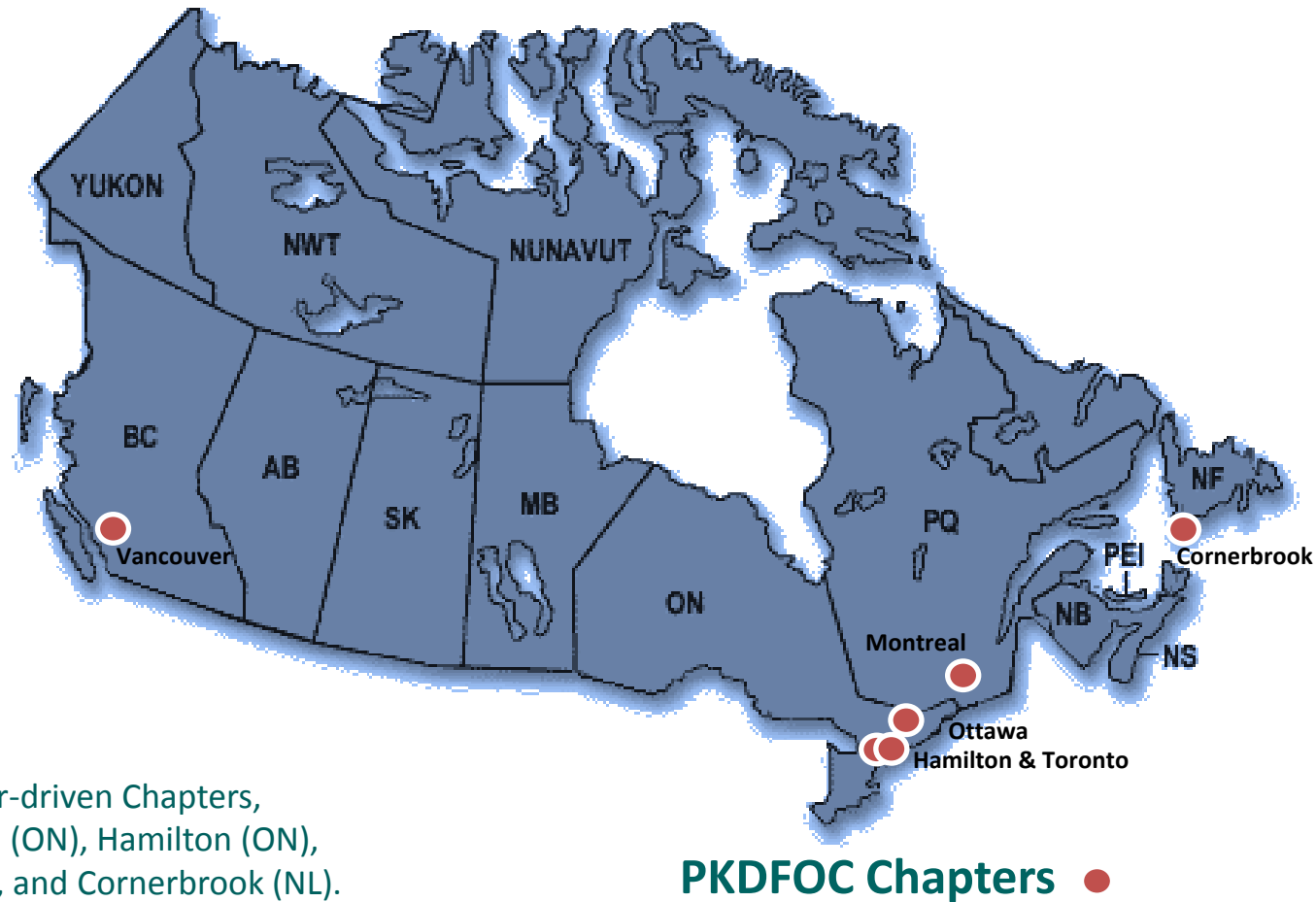
Jeff Robertson
Executive Director

About the PKD Foundation of Canada

The PKD Foundation of Canada is the only organization nationwide solely dedicated to raising awareness and funds for critical PKD research and patient education.

Over the last five years, the PKD Foundation of Canada has grown from a provincial organization with one Chapter in Toronto, to a National organization that continues to grow across Canada.

We currently have six volunteer-driven Chapters, including Toronto (ON), Ottawa (ON), Hamilton (ON), Montreal (PQ), Vancouver (BC), and Cornerbrook (NL).



Opportunities

Funding & Attaining Grants

- While we have been able to grow our revenue by 224% in four short years, there is still a great need for the organization to develop this area of outreach.
 - In 2014, the PKD Foundation of Canada purchased grant out-sourcing software to help them target opportunities that align with our mission and mandate. We've already been successful in obtaining grant funds from external sources and we look forward to increasing funds that come from this channel in the future.

Staffing

- For the past 6 years, the PKD Foundation of Canada has remained a staff of one. While we have been able to accomplish a great deal in this time, we realize that for us to make the largest impact possible on a National level, our staffing structure needs strengthening.
 - The Board of Directors is evaluating the potential of hiring a second staff member to assist in the day-to-day operations.

National Visibility & the Establishment of New Chapters

- The PKD Foundation of Canada has grown from one chapter to six, situated across Canada and we want to increase our geographic footprint to better meet community needs.
 - Through continued networking with members already in our database and new contacts, we are actively promoting our services in kidney clinics and dialysis centres across key cities that do not have a chapter presence to date. By establishing new chapters, this will enable us to engage new volunteers and donors, while also providing a new level of support on a local level to the PKD and medical communities .

Achievements

Fundraising

- Held our signature fundraising event, the Walk for PKD, in Guelph (ON), Vankleek Hill (ON) and Toronto (ON).
- 760 pairs of shoes laced up and 5 million steps were taken to end PKD, raising over \$162,000; 108% of our fundraising goal.
- Hosted the first *Shoot for an End* fundraiser in the Montreal Chapter, which included a professional photo-shoot / silent auction event, raising over \$3500.

Programs and Services

- Hosted educational support meetings in our Hamilton, Toronto and Vancouver Chapters, covering a wide range of topics related to PKD with medical experts from their local communities.
- Hosted Canada's very first National PKD Symposium.
- Launched our first Quebec-based chapter in Montreal, and developed French educational literature.

Advocacy

- Received recognition from Health Canada to make September 4th National PKD Awareness Day on an annual basis.
- Benefitted from 22 media hits, 2 front-page stories and 3 million media impressions, all emphasizing the need for treatment options in Canada.
- Represented the PKD community on a local level at various public events and exhibitions throughout the year.

Grants

- Funded the second year of Dr. Moumita Barua's translational research fellowship at Toronto General Hospital's Hereditary Kidney Disease (HKD) Clinic.
- Helped to expand the clinical care provided to PKD patients in the Greater Toronto Area.
- Collaborated on a financial level with the Division of Nephrology and Department of Medicine for the first time, directly supporting the PKD community.

Our Guiding Principles

Mission

To promote programs of research, advocacy, education, support and awareness in order to discover treatments and a cure for polycystic kidney disease; and to improve the lives of all those affected by PKD.

As a leader in the field, the PKD Foundation of Canada contributes to this mission by:

- Funding critical Canadian research into treatments for PKD.
- Developing educational and support resources for PKD patients and their loved ones.
- Strengthening the visibility of the PKD community on a local and national level through our Chapter initiatives.
- Providing the PKD community with the tools and platforms needed to host various fundraising campaigns.

Vision

No one suffers the full effects of PKD.

Governance

The PKD Foundation of Canada is a registered Canadian Charitable Organization (BN: 852683583 RR 0001)

The Board of Directors currently has six members including a Chairperson, a Secretary, a Treasurer, and three Directors. Board Members each serve a three year term and are appointed or elected at the AGM.

A Family's Sentiment

"The Foundation and my local chapters of Hamilton and Toronto have been a huge support to my family and me over the last few years, since my renal failure due to polycystic kidney disease.

Chapter meetings are very helpful and informative. Hearing about other people's experiences living with PKD has meant so much to me. The Foundation's members have helped me to no longer feel alone in my journey with PKD. The friends I have made from this group have become a second family to me!

My family and I have become very involved with the Foundation, and we very much enjoy helping! I have shared my journey living with PKD at chapter meetings and Walk for PKD events, as my desire and passion is to share what it is like living with this genetic disease.

I also share what it was like while waiting on dialysis for a kidney transplant, as this too is often the case for so many PKD patients. My husband, Don has also shared what it was like being a caregiver, and what it was like for him to be a living kidney donor for me.

Having this Foundation's support system available to us in the PKD community means so much, especially to those who are newly diagnosed with PKD."



- Lori Kraemer, PKD Patient & Transplant Recipient

Grant History

Year	Award	Researcher	Institution	Location	Project	Amount
1999	Grant	Dr. York Pei, MD.	Toronto General Hospital	Toronto, ON	Genetic modifiers for progression of ADPKD.	\$30K
2000	Grant	Dr. Marie Trudel, PhD	Clinical Research Institute of Montreal	Montreal, QC	Molecular genetics of PKD1 gene.	\$40K
2003	Grant	Dr. Zhen Chen, PhD.	University of Alberta	Edmonton, AB	Structure-function and regulation of polycystins and fibrocystins.	\$32K
2007	Fellowship	Dr. Qiang Li, PhD.	University of Alberta	Edmonton, AB	Signalling and modulation of polycystin-2 by Rho GTPases.	\$40K
2010	Grant	Dr. York Pei, MD	Toronto General Hospital	Toronto, ON	Patient registry database to enhance PKD research capacity.	\$25K
2011	Grant	Dr. Marie Trudel, PhD.	Clinical Research Institute of Montreal	Montreal, QC	In vivo analysis of ADPKD pathologies for development of therapies.	\$47.5K
2012	Grant	Dr. Marie Trudel, PhD.	Clinical Research Institute of Montreal	Montreal, QC	In vivo analysis of ADPKD pathologies for development of therapies.	\$47.5K
2013	Fellowship	Dr. Moumita Barua	Toronto General Hospital	Toronto, ON	Translational Research Fellowship in HKD.	\$35K
2014	Fellowship	Dr. Moumita Barua	Toronto General Hospital	Toronto, ON	Translational Research Fellowship in HKD.	\$14.8K

2014 Grant Recipient

In 2014, the PKD Foundation of Canada awarded the University Health Network and Toronto General Hospital's Hereditary Kidney Disease Clinic with a second one-year translational research fellowship for Dr. Moumita Barua. This award was co-funded by the PKD Foundation of Canada, the Tuberous Sclerosis Canada, and the University of Toronto's Division of Nephrology in the Department of Medicine, with the PKD Foundation of Canada contributing \$14,800 towards this grant.

Dr. Moumita Barua completed medical school, residency and nephrology fellowship at the University of Toronto. Her interest in hereditary kidney diseases was developed during her nephrology fellowship after completing a research project in autosomal dominant polycystic kidney disease (ADPKD) with Dr. York Pei.

University Health Network is the largest healthcare institution in Canada and comprises of four University of Toronto affiliated hospitals, Toronto General Hospital, Toronto Western Hospital, Princess Margaret Hospital and Toronto Rehab. Within this framework, Toronto General Hospital houses the first specialty clinic in Canada dedicated to the care of patients with HKD. This clinic is currently following more than 200 ADPKD patients and their families, many of whom have participated in one or more of their research studies. This clinic is designed to couple clinical care with research so that new knowledge for the benefits of their patients can be generated.



Dr. Moumita Barua,
PKDFOC 2014 Grant
Recipient

In partnership with:



UNIVERSITY OF
TORONTO

Advocacy & Awareness



National PKD Awareness Day

For the very first time, Health Canada recognized September 4th as National Polycystic Kidney Disease (PKD) Awareness Day – a special day devoted to raising awareness of this life-threatening, genetic disease.

We encouraged the PKD community to join in the conversation online, and thanks to a highly engaged social media and marketing campaign, the PKD Foundation of Canada achieved record-setting visibility including:

- 141,000+ views of our YouTube PKD Awareness Day campaign video
- Over 5 million online impressions from related articles and Canadian News Release pick ups
- Online and print coverage in the St. John's Telegram, Metro Ottawa and Vankleek Hill Review
- An on-air interview over 590 Newstalk



Advocacy & Awareness (cont.)

Working with the Media

Over the course of 2014, PKD Foundation of Canada staff, along with dedicated volunteers and PKD patients shared their PKD journeys through a variety of venues. These included television, print media and radio interviews, as well as patient testimonial videos that helped to depict what it is like to be impacted by PKD.

Topics covered included:

- *National Kidney Month, World Kidney Day and National PKD Awareness Day.*
- *Local Chapter educational events and meetings.*
- *The Walk for PKD campaign and Chapter fundraising initiatives.*
- *Families searching for living kidney donors.*
- *Post-transplant success stories and organ donation awareness.*



Advocacy & Awareness (cont.)

2014 Canadian PKD Symposium

In November of 2014, the PKD Foundation of Canada hosted Canada's very first PKD Symposium, in Toronto ON. More than 130 PKD patients, care-givers and medical professionals were in attendance, and heard from Canadian and International Key Opinion Leaders in the field of polycystic kidney disease.

A recording of the symposium was made accessible online, allowing individuals from across the country accessibility to this informative event.



Pediatric Nephrologist, Dr. Lisa Guay-Woodford discusses how ARPKD and ADPKD can impact a patient.

Topics included:

- Eating Healthy with PKD
- Learn the Facts: The Basics of ARPKD & ADPKD
- Understanding Living Kidney Donation
- An update on Canadian Clinical PKD Research
- Dealing with the Emotional Aspects of Living with a Chronic Disease



Renal Dietician and PKD patient, Kelly Welsh shares recipes from her cookbook, Brilliant Eats.

Fundraising

2014 Walk for PKD: Campaign Results

Throughout the month of September, 760 attendees, including PKD patients, their families and friends, joined us for the PKD Foundation of Canada's signature fundraising event, the Walk for PKD! More than \$162,000 was raised in 2014, reaching 108% of our fundraising goal!

The money raised from this year's campaign allows us to continue funding the much needed Canadian research in developing future treatments for PKD, while also strengthening our educational support to patients across the country. Without the support of our generous donors and corporate sponsors, this would not be possible.

A heartfelt thank you goes out to all of our passionate volunteer Walk and Chapter Coordinators and their committees, our corporate and in-kind sponsors, and every single participant who walked to end PKD!



Fundraising (cont.)

2014 Walk for PKD: Corporate Sponsorship



A very special thank you goes out to **Otsuka Canada Pharmaceutical Inc.**, who generously became our **UNDERWRITING SPONSOR** in 2014; donating \$30,000 to the campaign. Once again, members of Team Otsuka attended the Toronto Walk for PKD with their families to show their commitment and support of the PKD community!

Scotiabank - Vankleek Hill once again matched \$5,000 towards the Vankleek Hill Walk for PKD campaign and served as our **GOLD SPONSOR**. In addition to this generosity, they also hosted an on-site bake sale to raise additional funds earlier in the month, and provided on-site volunteers to provide support on Walk Day. We truly appreciate their continued support and their unwavering dedication to the local PKD community.



Fundraising (cont.)



Chapter Fundraising Spotlight: The Montreal Chapter's *A Shoot for the End*

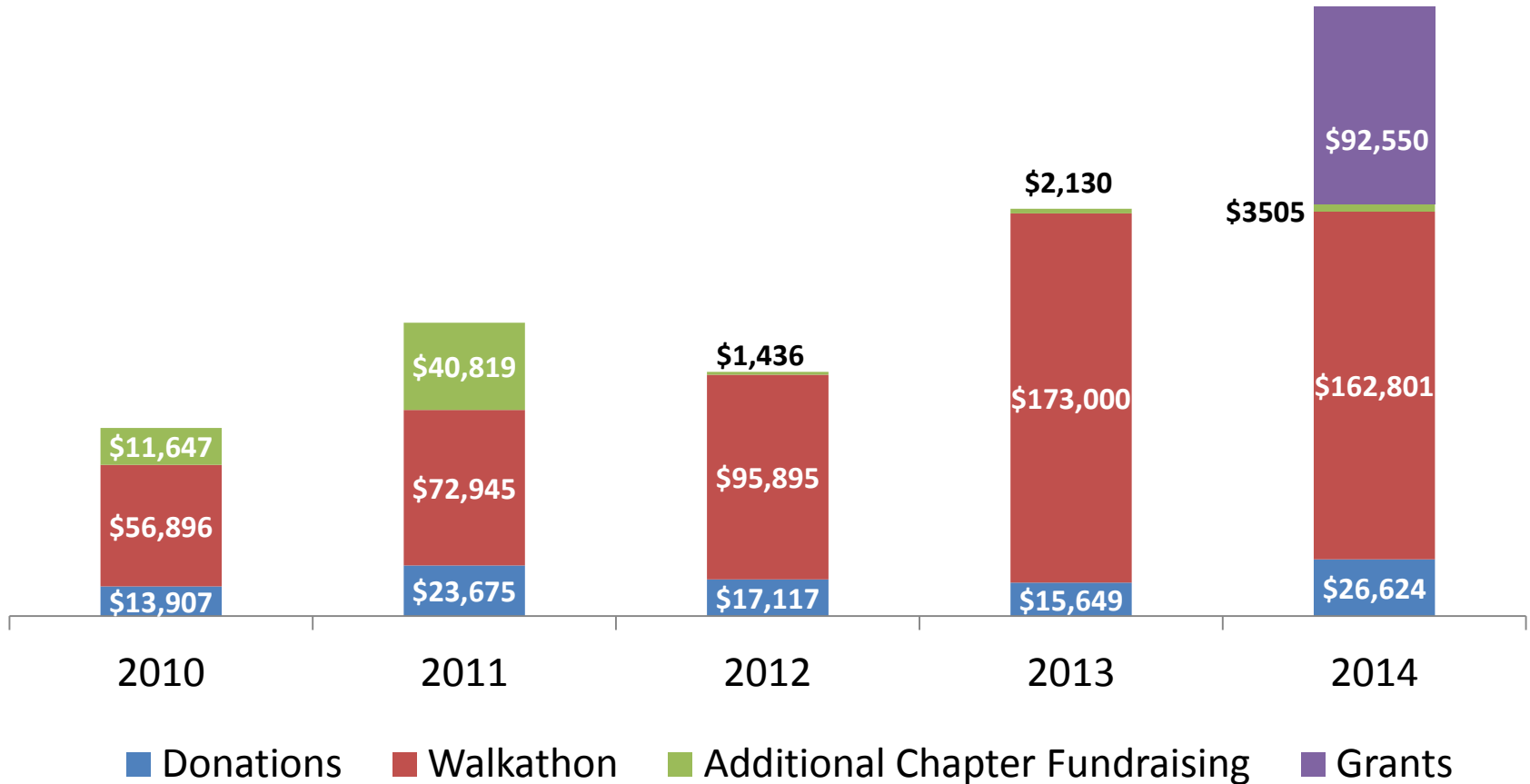
In August, the newly launched Montreal Chapter held their first fundraiser, dubbed 'A Shoot for the End'. At this event, attendees had the opportunity to purchase a professional photo shoot package for themselves or their family and friends, with all proceeds going towards the PKD Foundation of Canada. Thanks to the in-kind support of the on-site photographer, hair stylist and make-up artists, we were able to direct more funds exactly where the donor intended for them to go – towards critical research into treatments for PKD.



This was a wonderful way to kick things off in Montreal, and a huge thank you goes out to Chapter Coordinator, Luisa Miniaci Di-Leo and her incredible family who helped to make this inaugural event a smashing success! 'A Shoot for an End' was able to raise more than \$3500 and helped to generate invaluable awareness of both the PKD Foundation of Canada and their local chapter

Financial Reports

Comparative Contributions

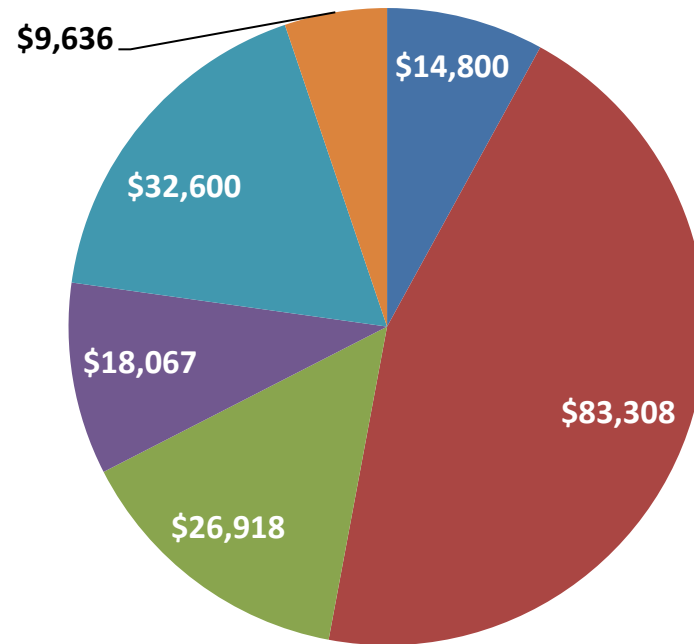


* 2010 fundraising values include Ottawa Chapter fundraising events which did not take place over 2011, 2012, 2013, or 2014

* 2011 fundraising values include the one-time Richmond Hill Mayoral Golf Tournament revenues which were \$40,000.

Financial Reports

2014 Expenses



■ PKD Research Grants

■ Fundraising

■ Foundation Growth / Development

■ Member Services and Education

■ Chapter Management

■ Accounting, Legal and Insurance

**A total of \$54,438 (staff salary, EI and CPP) has been allocated into areas where the E.D's time and attention has been focused.*

Our Team

Executive Director: Jeff Robertson

Jeff has been the Executive Director of the PKDFOC since July 2008. He is the Foundation's sole staff member, and the driving force responsible for the success the Foundation has enjoyed over the past five years. Jeff serves as the lead role in the implementation of the Foundation's long-term strategic initiatives, and manages all day to day operations of the PKD Foundation of Canada.



Chairman: Michael Kenigsberg

Michael has been a member of the Board of Directors since 2010. He currently works as a Management Consultant at a global firm focused on pharmaceutical and healthcare clients.



Secretary: Christopher Neuman

Christopher has over 30 years of progressive experience in the Canadian pharmaceutical, medical device, and biotech, most recently in senior executive leadership roles (12 years P&L responsibility). Amongst his many accomplishments, Chris has written clinical research protocols, led FDA submissions, launched numerous Branded and Generic products, led numerous BD activities acquiring and disposing of products and businesses, set up several national sales forces, led marketing efforts in the American and off shore markets.



Treasurer: James Baird

James joined the Board as Treasurer in August of 2011. James currently works for a global enterprise software firm, focused on go-to-market strategy creation and business development. He holds an MBA from the Ivey Business School at Western University, and is a CFA Charterholder.



Our Team

Director: Joseph Brant

Joseph was born and raised in Toronto, ON with strong ties to both of his parent's reservations, Tyendinaga Mohawk Territory and Wikwemikong Unceded Indian Reservation. Prior to joining the Board of Directors in 2012, he was the volunteer Toronto Chapter Coordinator from 2009 to 2013.



Director: Antonella Rizza

Antonella joined the Board of Directors in January 2013. Her personal connection to PKD was first identified when her father was diagnosed with a rare mosaic form of PKD (PKD in only one kidney). Antonella is a partner in the KPMG LLP Toronto offices. She has specialized in areas of financial statement auditing, US GAAP, Private Business GAAP, International Financial Reporting Standards (IFRS) and Securities Offerings. She has experience working with public, private and not-for-profit organizations.



Director: Doug Robertson

Doug is a senior manager in the consumer packaged goods industry, and has served as a board member of the PKD Foundation of Canada since 1994. He is a past Chairman of the Board of Directors. Doug resides in Richmond Hill, Ontario with his wife Jan and is a founding member of the PKD Foundation of Canada.



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